

Rapid Review

Transition for young people with learning disabilities in housing, social care, and health care, education/training, and employment

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30 May 2018

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Executive Summary

Transition for young people with learning disabilities remains a difficult process for everyone involved. It is widely recognised that transitions impact on several life domains at different times: education, health and social care, as well as employment and housing. These service transitions take place before the background of significant biological and developmental changes for young people.

The needs of young people with learning disabilities during the time of transition vary considerably depending on the severity of their disability and the availability of social support they can draw on. There has been substantial research and policy around transition for young people over the last two decades. A sizeable number of transition studies has been conducted producing good evidence as to the needs of young people with regard to employment, education and health and social care.

The Children's Commissioner for Wales asked a team led by Dr Axel Kaehne of Edge Hill University to obtain and analyse existing evidence around transition for young people with learning disabilities in four distinct yet interrelated domains: education, employment, health and social care and housing.

The research team proposed to conduct a rapid review of published peer reviewed and grey literature to obtain information about the following four questions:

1. What are the needs of young people with learning disabilities during times of transition from children's to adult sector provision in housing, education and training, health and social care and employment?
2. Which positive support for young people with learning disabilities and their support networks is currently available in Wales and what is considered best practice?
3. What are the gaps in support provision in Wales for this population and how can it be addressed?
4. What should be the priorities of future work by the CCfW in the field of transition and how can it best be facilitated with the existing capacity in Wales?

The review produced robust evidence about transition needs of young people in three domains: education, health and social care, and employment. Housing transitions emerged as a distinctly under-researched area for this population.

Educational transitions remain the cornerstone of transition planning for young people with learning disabilities and the most visible part of their transition experience. Planning of transition starts around the age of 14 and there are a number of well developed and validated tools to facilitate transition planning in schools. The numbers of young people actually involved in transition planning through person-centred planning processes however still appears to be low, and transition plans are often specific to educational transition. Fully integrated transition planning across health, social care, education and employment is extremely rare.

For most young people with learning disabilities transition to employment occurs after college. Whilst some schools organise exemplary work placements in the community, colleges may or may

not identify suitable placements for young people in real life contexts. A significant barrier to successful transitions into employment remains the fact that the statutory transition process does not continue beyond college graduation for many young people with learning disabilities. This makes it difficult to plan ahead and develop meaningful employment options for some young people who want to work after college. There is however robust evidence that supported employment, where delivered effectively, produces good employment outcomes for young people with learning disabilities at all levels of functioning.

The review found a significant amount of evidence regarding the social and health care transition of young people. It is widely felt that joint clinics between children's and adult health care providers are perceived as positive by young people and their families. Overall, however the field of transition is marked by service fragmentation, differing eligibility criteria in the adult social care sector leading to a reduction of services for some young people and underprepared or underfunded adult specialist health care services which struggle to cater for the particular needs of this population. In addition, mental health provision for adolescents remains a persistent and serious service gap for young people with learning disabilities. The issue of continuity of care is often addressed by retaining young adults in child services in the NHS, in particular in specialist paediatric settings. This however creates issues around suitability of services and costs.

Housing is the only domain that offers little robust published evidence on transition of young people with learning disabilities. There is some research around out-of-area placements and the impact of those on young people's pathways through education. However, the housing needs of young people and how to accommodate a growing young population with learning disabilities is currently not adequately reflected in research and evaluation studies.

The researchers note the following gaps in evidence, which will be useful points of consideration for researchers and Government:

- Evaluate the impact of the Welsh additional learning needs strategy on transition planning and transition outcomes for young people
- Obtain and analyse data regarding transition outcomes/destinations for young people with LD in Wales
- Explore the barriers to include all young people with LD in their transition planning in school and FE colleges
- Obtain national data on destinations and transition outcomes of school leavers and those leaving colleges to ascertain access rates of young people to employment support
- Examine the facilitators and hindrances to include SE employment options in the transition planning for every young person in school and college
- Identify suitable ways to disseminate best practice in supported employment across Wales and facilitate shared learning in the field
- Gather relevant data on health transitions of young people with LD in Wales
- Review transition tools developed by Welsh local authorities and health care providers and assess their effectiveness
- Obtain and analyse relevant Welsh data pertaining to housing transitions
- Identify capacity of the housing sector to provide suitable supported living opportunities for young people in line with future demand
- Identify trends in, and reasons for, out of area/residential placements for young people moving from school to college

Background

Transition of young people with learning disabilities remains a process fraught with problems and challenges for the young people, their parents and carers as well as their wider social networks. Transition is commonly defined from the perspective of services which provide support to young people but it is also a biological and chronological process for the individuals. Service transitions occur at different times for different individuals depending on the severity of their disabilities, the availability of support and the receptiveness of adult services into which young people are supposed to move.

Despite significant policy attention from the Welsh Government and Central Government, dedicated transition support remains fragmented along service sector lines and holistic service planning is rare.

The Children's Commissioner for Wales commissioned this rapid review of published evidence to identify the needs of young people with learning disabilities, the availability of positive support across Wales and gaps in service provision.

Research Aims

This rapid review produces information about the needs of young people with learning disabilities during transition, the availability of positive supports, and gaps in service provision in Wales. It also identified priorities for future work. Where possible information relating specifically to the Welsh context was to be highlighted throughout the document.

Rapid Review Questions

5. What are the needs of young people with learning disabilities during times of transition from children's to adult sector provision in housing, education and training, health and social care and employment?
6. Which positive support for young people with learning disabilities and their support networks is currently available in Wales and what is considered best practice?
7. What are the gaps in support provision in Wales for this population and how can it be addressed?
8. What should be the priorities of future work by the CCfW in the field of transition and how can it best be facilitated with the existing capacity in Wales?

Methods

Given the short reporting timeline, Edge Hill University was asked to conduct a rapid review. Rapid reviews originate in systematic review methodologies (Khangura et al. 2012). They are a well established technique to synthesise evidence in medical research (Kaltenthaler et al. 2016; Varker et al. 2015; Watt et al. 2008), and are becoming increasingly common in the field of public policy formulation and policy impact evaluations (Ganann, Ciliska, and Thomas 2010; Moore et al. 2018). Rapid review methodology is currently a non-standardised type of systematic review with various types of reviews subsumed under the conceptual umbrella of rapid review (Harker and Kleijnen, 2012; Tricco et al., 2015). We have followed a rapid review format that is now widely accepted amongst health care researchers (Harker and Kleijnen 2012; Tricco et al. 2015).

The key difference of a rapid review to a systematic review is that one component of the systematic process formulated by PRISMA¹ is shortened or omitted entirely. A key requirement of rapid reviews is to provide transparency to commissioners about which component of the systematic review method was altered to achieve rapid turnaround of results.

In our case, we have conducted a rapid review of publications in the field of transition in accordance with the PRISMA standard yet omitted the quality appraisal of published data. Since much of transition research is based on qualitative and small scale studies, a quality appraisal of evidence would have limited discriminating power. We therefore felt that the quality appraisal would have contributed little to the scope, quality and depth of the findings. Omitting the quality appraisal stage in rapid reviews is an accepted and common procedure in rapid reviews (Harker and Kleijnen 2012; Tricco et al. 2015). In addition, title, abstract and full text screening was carried out by one single researcher rather than two researchers. This is an accepted way to expedite the screening process in rapid reviews.

Search strategy

A search strategy was developed in consultation with the Clinical Information Specialist. The search was then applied to 15 relevant databases. Policy and grey literature were captured through NICE Evidence Search, HMIC, Social Care Online, Discover More and a 'rapid' Google search. Eight key journals were also hand-searched. Appendix 1 provides details on all resources searched. An example of search terms used for the search is in appendix 2. Only publications in English were selected. Papers published after 1990 were included.

Criteria for inclusion/exclusion were as follows. Papers reporting studies that did not focus on transition of young people with learning disabilities were excluded. Learning disabilities were defined broadly with multimorbidity studies (young people with autism or other morbidities) being included as long as there was a clear indication that young people with learning disabilities were part of the study sample. For papers originating in the US and Canada, the term *intellectual disability* or *developmental disability* was taken as synonymous with the term *learning disability* conventionally used in the UK. Papers authored in the US referring to *learning disabilities* were excluded as this term relates to learning difficulties, such as dyslexia, in the US context, which is

¹ <http://prisma-statement.org>

not regarded as a learning disability in the UK. All types of study design and methods were included as well as non-empirical papers such as commentaries and position or discussion papers.

Analysis

Search results were then analysed by one independent researcher. The search identified 2899 documents. After removing duplicates and non-English publications, there were 2879 papers remaining. The title screening was conducted first, with all papers categorised at this stage into four clusters: education/training, employment, health and social care and housing. We also created a category of general papers where the title indicated some relevance to more than one investigative clusters. Following title screening, 485 papers remained. This included 36 general papers, 86 papers in health and social care, 57 papers in housing and 113 papers in employment related transition.

Abstract screening was then conducted by a researcher. Following abstract screening, 8 papers remained in the general paper category, 8 in social and health care, 4 in housing, 20 in employment, and 32 in education. Full text screening revealed that some additional papers had to be excluded because of non-relevance to transition or because they were obtainable. The full text screening resulted in the inclusion of the following number of papers in the analysis: general papers 6; social and health care 6; housing 3; employment 17; and education 26. The table below details the results after each screening phase.

Table 1: Search results by search stage

| | General Papers | Education | Employment | Health and Social Care | Housing | Total number of papers |
|---|----------------|-----------|------------|------------------------|---------|------------------------|
| Included after title screening | 36 | 193 | 113 | 86 | 57 | 485 |
| Included after abstract screening | 8 | 32 | 20 | 8 | 4 | 72 |
| Included after full text screening | 6 | 26 | 17 | 6 | 3 | 58 |

Full text analysis was conducted by three members of the research team. Relevant paper content was identified, summarised and categorised within each cluster. A narrative was written for each research question in each cluster and discussed with in the team. Following clarifications, the final narratives for each cluster were produced.

The papers included in the analysis comprised mainly qualitative studies (n=43), echoing the predominant exploratory research paradigm and research focus in learning disabilities studies on recording and documenting the experiences of young people and their families. Only three papers championed a quantitative approach, one of those conducting a secondary analysis of public datasets. There were also two reviews of existing literature, one of which was a systematic review of evidence. Seven pieces of work included in this review were commentaries or written work

synthesizing other published evidence, one of these was a monograph, and three included studies were conducted using mixed methods.

In terms of geographical origin, the review included 35 papers from the UK, 8 papers from European countries, 14 studies or commentaries the originated in the US or Canada, and 1 paper from elsewhere (Israel).

Results

In line with the agreed study protocol we report the results of the analysis in four clusters and four subgroups. The clusters relate to the four service sections that are under consideration for the transition study: education, employment, housing and health and social care. Each cluster is then subdivided into four categories relating to the research questions: what are the needs of young people in transition; what are the positive supports available; which service gaps exist; and what should be priorities for future work.

We have highlighted findings that specifically relate to Wales in separate boxes within the text. A general section of findings has been added at the end of the results. It contains findings from the analysis that capture the wider context of transition planning which we believe is important for the Commissioner to consider.

Education

General context

Education remains the main location of the statutory transition planning process for young people with learning disabilities (LD). Educational institutions also offer the most substantial resources to plan transition for this population. There has been an abundance of policy guidance and resources spent on educational transition. More recently, policy has tried to combine transition planning in education with transition planning of health and social care, as well housing and employment championing an holistic approach to the issue.

In the literature the transition planning in education discusses various types of transition; from school to college education; from education to employment; or from in-area educational providers to out-of-areas residential providers. In the section below we distill the findings that apply to all types of transition planning in education unless otherwise stated.

The needs of young people

There is a strong consensus in the literature that person-centred planning is a prerequisite for successful transition for young people with LD. The argument is based on the observation that the population of young people is heterogenous in their needs and thus requires individually tailored solutions that only a person-centred planning approach can deliver. There are some voices advocating a family-centred approach instead of, or complementary to, a person-centred approach but there are arguments against such a change in the literature as well since it would undermine the general assumption in much of transition planning that young people with LD should be presumed to have the capacity to be treated like normally developing adolescents and adults.

The literature also makes clear that a significant number of young people are still excluded from transition planning. Figures quoted in this context are as high as 40 percent. This demonstrates that for many, the transition process is still planned *for* them, rather than with them and by them.

The predominant needs of young people in educational transition are to be included in the process, to be heard and to be given meaningful choices. An important part of all successful transition planning is for young people and their families to be kept informed throughout the process and the literature highlights that many young people and their families are left in the dark about the future until very late in the day. A lack of information about the options available to young people is also an ongoing concern to many observers.

The literature also identifies families as a key facilitator for successful educational transition planning which can only work if parents and young people are kept in the loop, their social network is involved proactively, and where young people are heard and listened to in the process.

In terms of educational skills and service needs, young people with LD in transition require effective self-determination skills which can be delivered through training in educational settings, as well as robust interagency collaboration to ensure that everybody is on board and committed to the identified transition goals.

Available support for young people

There is agreement in the literature that the support structures for educational transition are better developed than those of other transition domains. The significant amount of policy formulated for educational transition has clearly made an impact on the transition process over the last decades and the quality of outcomes. However, observers note that there are significant challenges that originate in the way in which supports are structured and how available resources predefine outcomes.

There is good evidence that schools have improved considerably the quality of transition planning for their pupils, and have recourse to a plethora of transition tools. This has brought about some examples of outstanding transition practice. However, it remains the case that schools still struggle to provide good transition planning for everyone. In particular, young people with different functional abilities may not receive the same high-quality transition planning. In the literature this is reflected as a result of different, higher support needs of young people with severe and profound LD, whereas those with mild LD who may be in mainstream educational providers may receive less support than those in special schools which, again, has an impact on the transition planning and support available.

These differences in outcome may reflect deep structural differences in resource allocations and/or transition planning processes for different subpopulations and indicate that person-centred planning may be a reality only for a minority of young people, most likely those with moderate or severe LD in special schools.

The literature specifically mentions the critical role careers services play in transition planning and the evidence is not clear whether careers services meet their obligations of delivering meaningful career advice to young people with LD consistently. It appears that where careers services are proactively part of the transition planning and develop meaningful options for young people's post-school placements, transition outcomes improve and are seen as positive by young people and their families. Where careers services fail to be part of a person-centred planning process, their service is perceived as largely redundant.

The literature also points to a largely underused resource in transition planning. Researchers note that existing social networks and family networks may function as considerable sources of support. This message aligns with increasing emphasis placed on asset based approaches in social care and should constitute part of any educational transition planning.

Some literature also stresses that schools have developed good relationships with employers in their local area to facilitate work placement as part of the transition process. This is thought to help young people develop preferences and, ultimately, positively informs the planning process (see below section Employment).

Service gaps

There is a significant amount of mixed messages in the research literature about where the gaps in service are in the educational transition. This may reflect the enormous regional and local variations in available resources, differences in provision in urban and rural areas as well as other local factors. However, as for educational transition, the main dividing line runs between mainstream and special schools. Differences in provision appear to be larger between these two types of educational settings than between others, say, rural and urban.

There is however agreement that, whilst educational transition is the most developed type of transition, it remains poorly linked with the transitions of young people in other life domains, such as housing, social care and employment. Observers usually do not see this as a fault of education transition planners but as a result of the inability to merge transition planning across all services into one holistic process. Time constraints are often cited as the main reasons why staff from other services are often unable to attend school transition planning meetings. It appears that these barriers are unlikely to be lifted given the wider context of limited resources in social and health care and it may be useful to develop alternative solutions to this problem.

There is also a consensus that where transition planning occurs and is done well, follow up is often not as effective. Where transition options fail to materialise, families are often left struggling. Lack of follow up is identified as an important shortcoming of current transition planning. This relates to follow up by careers services as well as educational providers.

Another gap of current service provision relates to the significant variation of services across the wide spectrum of needs. The literature repeatedly contains concerns that some parts of the population, such as those with mild LD in mainstream educational institutions, are not properly supported. In this context, researchers point out that transition outcomes should be investigated through a stratified approach in order to identify segments of the population that may receive less effective transition support simply because of their level or type of LD.

An additional gap in the provision of transition support is a lack of support around the development of choices and preferences for young people with LD. Such a lack of preferences may make effective and inclusive transition planning difficult and prompt parents and staff to select further education (FE) colleges or residential colleges as the next destination for most young people during transition planning. Whilst this may be appropriate for some young people, it runs counter to the commitment of person-centred planning based on young people's choices.

Evidence in the Welsh Context

The published literature originates mainly in studies conducted in the UK, US and Europe. There are some studies conducted in Wales but none qualified for inclusion in this rapid review. Whilst we are confident that the messages around young people's needs and support available also apply to the Welsh context, there are some considerable differences in the educational system between Wales and other constituent parts of the UK that would warrant detailed analysis. In particular, we are conscious that the impact of the Welsh Government's policy around additional learning needs and the guidance relating to follow up of young people's transition up to the age of 25 is not captured through an analysis of international or UK evidence.

Priorities for future work

The need for data on the destinations of young people with LD following transition is often identified as an important priority for future work. This relates to the need for follow up and to understand which educational transition support works for whom and why. There is also a lack of evidence regarding what alternatives and choices are offered to young people during the transition planning and how these options are actively developed with the young people prior to planning meetings.

The most important concern remains however why many young people are not included in the transition planning process and how this can be rectified. The planning process is time consuming, resource intensive and remains sector specific and poorly integrated across life domains. The question is why educational institutions continue to struggle with providing meaningfully inclusive practice in this area and why holistic planning processes remain rare. Given the considerable amount of transition guidance and policy for schools, it may be useful to develop alternatives to current policy and guidance.

Whilst most observers agree that young people should be included in the process, achieving this will require different types of efforts given that consistent efforts to improve inclusion in transition practice has not achieved this for everyone. Equally, creating a fully holistic planning process may not be feasible given the time and resource constraints on social and health care staff. Instead it may be helpful to explore whether technology-based options such as electronic transition care plans accessible to all services may offer better solutions.

Employment

General context

Employment for young people with LD is a relatively well researched field and there is sufficient evidence to draw robust conclusions for further priorities in general and for transition into employment in the Welsh context in particular. Employment is also the area where people with LD fare worst in comparison with the general population with employment figures for the adult population with LD ranging from 7 to 12.5 percent. The latter figures possibly includes part time and voluntary work (Beyer 2005; Beyer and Kaehne 2008).

There is also a clear consensus amongst researchers and observers that what works in employment for young people with LD is supported employment and that generic employment services are inadequate for this population. The lack of specialised support in this field for many young people with LD is a likely contributor to the high number of young people not in education, employment or training (NEET) in this population, most of them simply staying in the family home without any meaningful involvement in work related activities.

Transition to employment is thus well defined, well researched but also shows the least satisfactory outcomes. In contrast to all other transitions, such as health and post-school education, employment transitions are optional thus reducing pressure for services to develop this as a serious option for post-education day activity for young people with LD. The transition to employment also often takes place after the statutory transition planning process at an age where young people have grown into adulthood. Efforts to lengthen the planning process to the age of 25 should have an effect on this, but there has so far been no published evidence in the public domain.

The needs of young people

The needs for this population in employment transition are well defined. Young people with LD are particularly vulnerable to transitions into 'nowhere' following graduation from college. They are likely to be neither in education, employment or training when becoming adults. They require specialist, tailored support which is ongoing, and address their needs.

In order for young people to transition into employment, they require support to develop their vocational preferences, to take up and sustain work placements and work experiences at an early stage (ideally when still in school), as well as acquire sufficient self-determination skills and general life skills to obtain and hold down a job on an ongoing basis.

The services needed to deliver these requirements are: individually tailored employment support including effective job coaching, a clear pathway into employment set out by transition planning which allows the young person to weigh options and make an informed decision, and follow up support and/or continuity of support in supported employment (SE) placements where needed.

None of these are provided as a matter of fact for young people with LD at present. Work placements are rarely developed by generic support services such as careers services, and where SE services are provided, young people with moderate LD are often selected over young people with more complex support needs.

In particular, the provision of pre-vocational training remains patchy. Where schools or colleges manage to identify work placements for young people these are often of short term nature and transition out of college into employment before graduation even where placements are deemed successful is extremely rare. Many schools or colleges also continue to place young people with LD in sheltered work environments, something that has been shown to deliver inferior employment outcomes for this population.

Access to effective supported employment is key to delivering employment as a destination for young people with LD. A clear indicator of employment as a primary outcome of transition support is whether young people have experienced working in a job during college.

The literature identifies additional support that contributes positively to employment transition outcomes. The availability of a mentor or peer mentor is seen as a significant factor in bringing about employment for young people with LD. Another important factor is a supportive family environment with parents and other family members in employment themselves. Examples from other (non-disabled) peers may also increase the willingness of young people to work or try out employment.

A considerable barrier to effective transition into employment remains the lack of good job coaching, a lack of knowledge on the side of families and young people about how to access support, and insufficient life skills or self-determination training in education.

Available support to young people

There is good evidence from other European countries that demonstrates the possibility of effective employment support for young people with LD. Studies from Denmark and Sweden show that continuous and ongoing support yields the best outcomes in this area. In Austria, and locally in some regions in Germany, supported employment services are integrated into the so-called dual system, which delivers training and employment in an integrated fashion based on a partnership between employers and vocational colleges.

There is also good evidence that work experience delivered in real life work environments is the most effective form of support for young people with LD. In addition, there are some signs that mentoring programmes help young people to cope with the demands of employment in the open labour market. In particular, peer mentors may be useful in this context as they shape young people and their families' expectations around work and having a job.

The most important support available however is supported employment (SE) agencies. They have shown to provide effective support producing positive outcomes. Providing these services to all young people with LD following school or college, however, remains difficult. SE agencies may provide services only to a select few, may get referrals only from 'suitable' young people or, work with young people only temporarily.

At present, the literature notes that the SE sector is far from delivering a standard service to all young people in close collaboration with educational organisations. This means that receiving SE services remains the exception and the employment pathway is underdeveloped and de-emphasised as young people move through transition planning.

The strongest type of support which has shown to facilitate good employment outcomes for young people is families. Where parents early on identify employment as a viable and desirable option of post-education transition, a job or work placement with support is more likely to materialise. This points to the critical role families have in determining the transition outcome and how the transition planning needs to articulate and develop employment options sufficiently early for parents and young people to perceive it as a viable option.

Service Gaps

The literature is agreed about the significant difficulties in providing sufficient support to young people with LD transitioning into employment. The literature points to a lack of adequate support, in particular SE opportunities. There is also a perceived lack of good job coaching and some observers note that there is a lack of clear standards of what constitutes good SE or job coaching. Job matching skills are also singled out as an important ingredient for good job coaching.

There is some discussion in the literature about whether rural areas are disadvantaged insofar as young people living in urban areas may be more likely to have access to SE services. However, there appears to be too little evidence to draw any conclusions in this regard.

There is agreement that generic services in employment do not provide adequate support for young people with LD. This goes for the Connexions service in England as well as the Careers Wales service. It is pointed out that employment can only be obtained and sustained by people with LD where they receive specialist and ongoing support.

There are some concerns in the literature that young people with severe and profound LD are not selected or referred to SE services at all. The assumption may be that they are not interested or not capable of working. However, there is clear evidence that SE works for people with LD regardless of their level of disability where individually tailored support is provided.

The literature also contains some references to particular challenges around employment for young people that relate to the general jobs market and geographical circumstances. There is an acknowledgement that high rates of unemployment in certain areas and the lack of effective transport links impact negatively on the ability of SE services to produce good outcomes. This highlights the need to conceptualise employment as a multifactorial outcome, depending on other types of local infrastructure.

Evidence in the Welsh Context

There is a significant amount of research on supported employment that has taken place within Wales or has relevance to Wales (Beyer et al. 2008). There are also SE providers in Wales who deliver services that can be identified as best practice. What is less clear by looking at the literature is whether any specific educational strategy by the Welsh Government has made an impact on SE provision to young people with LD. In particular, it remains unclear whether or not transition planning in schools and colleges maximise SE employment opportunities. Although there is some research around the need for the inclusion of SE into the statutory review process (Kaehne 2010; Kaehne and Beyer 2013), there is currently no evidence on how that is being achieved across educational providers.

Priorities for future work

There are some issues that receive particular attention in the literature requiring more research and work to improve employment opportunities for young people leaving education.

There is a need to investigate how to increase the provision of SE services and make this an ambition for every young person between 16 and 18. To achieve this, the role of SE in the transition planning process requires further analysis and definition. At present, SE services may only be invited to participate in transition planning as and when one of the stakeholder requests it. The option of employment should be a mandatory consideration for the transition planning process of each young person starting at the age of 16.

To ensure that employment is perceived as an option by both families and young people, schools and colleges need to develop real life work experiences with local employers. Part time jobs in the community may be particularly useful in this context and foster good relationships with local companies.

There is also a need for further research as to how peer mentoring can assist young people to transition into employment. The question should be whether mentoring works, for whom and under which circumstances.

The fact that employment rates for young people with LD remain extremely low requires a sea change in the way in which schools, vocational colleges and careers services approach this issue. At the moment, there appears to be a working assumption that most young people will transition out of school into a FE college. Transition planning then picks up the need for employment support during college attendance or just before graduation. At this stage, developing a preference for employment may simply be too late for young people as they can easily drop back into non-work related day time activities in the community or stay at home. Instilling employment as a personal ambition and as a viable transition aim requires early intervention, good planning and preparation as well as robust, ongoing support structures. How to provide this in the Welsh educational and post-educational care context remains insufficiently articulated in the literature.

Social and Health Care Transitions

General context

Transitions of young people with LD moving from children to adult social care and health care providers are not as well researched as educational and employment transition. However there is a substantial body of evidence that suggests various trends, barriers and challenges for young people moving on. The main issue is that children's social care is centred around families, with a strong emphasis of holistic care. Children's social services are also universal, free services entirely funded by taxation. Their adult equivalent in social care are co-funded by individuals depending on needs assessments and eligibility.

Health care remains free in the UK and Wales at the point of use. However, people with LD often struggle to access disability appropriate or disability sensitive services. There also continues to exist significant fragmentation between social and health care organisations which makes the navigation of services difficult, particularly for people with chronic and complex conditions or multi-morbidities.

There has been considerable experimentation in children's social care with key workers providing a central point of access to young people with LD. There is little in terms of equivalent experimentation in the adult sector. In addition, the adult health care provision is segmented along medical specialities which adds to the complexity of navigating the existing provider landscape for people with LD.

Transition into the adult social and health care provision remains a one-sided endeavour, where staff working in children's services prepare young people for transition to adult services. Adult services are often not involved in this planning at all, or, where they are involved, they represent singular specialities. The upshot is that the transition itself resembles a transfer, or handover, rather than a meaningful transition. Services on the adult side are also defined through eligibility criteria that remain often widely different from children's universal care provision. In many cases, these challenges of health and social care provision simply lead to a delay or postponement of transition of young people well into their twenties, or, as in mental health, to a gap in provision between the ages of 16 and 18.

The needs of young people

The needs of young people with LD during times of transition in health and social care are well documented. Young people want a smooth transition with as few interruptions to their care as possible. The health and social care transition may occur at the same time as their leaving school or FE college, but may also take place significantly later where no receiving care provider can be identified in the specialist adult sector.

The main challenge of transition remains to be one of different service structures between children and adult sector, different care approaches, different eligibility criteria and sectoral fragmentation in the adult provision. At the same time as young people experience biological changes, gain maturity and assertiveness, services in adult tertiary providers, such as mental health trusts, the

NHS and local social services operate differently to those in the children's sector. This often leads to a delay in transition from children to adult sector altogether or a ceasing of service.

A key mechanism to achieve smooth health care transitions are joint clinics between paediatricians and adult specialists. Since young people with LD often have multiple health care needs that cut across medical specialisms, the integrated care that they experienced in children's services often gives way to highly fragmented care, with young people now having to visit a number of different clinics and hospitals. Some care, such as physiotherapy and speech and language therapy (SLT), often simply ceases for a considerable time whilst needs assessments take place.

Research identified several ways to address some of the challenges around health and social care transition. The first one is simply to postpone transition. Some services routinely continue to serve their patients to the age of 25. This however only delays transition rather than facilitates better transitions. A second approach is to utilise a life span approach which would allow care staff in children's services to increase their patients' ability to self-manage their conditions.

The literature also identifies a specific subgroup of young people with LD which encounter specific difficulties in transition: young people living out of area. Their access to NHS and care services is fraught with particular challenges since they are often seen as only temporarily resident.

There are some comments in the literature about the need to provide a key worker on the adult side for young people with LD. One suggestion has been that the general practitioner may play this role. However, there is also substantial skepticism amongst observers that GPs have the training and skills to meet the requirements for effective key working for this population. Our analysis of existing published literature did not identify a sensible consensus amongst experts and commentators in this matter.

Available support to young people

The literature identifies few instruments or mechanisms that are proven to help bring about smooth care transitions for this population. Joint clinics are mentioned repeatedly but the main barrier to them is that adult care staff often do not have the time to attend them or fail to engage sufficiently early with patients before adult services take over.

There are also some examples of good transition planning in the social services for children, yet researchers and observers point out that even the best planning will struggle to make an impact where adult social services do not have the capacity and resources to provide similar levels and quality of service as young people received before transition.

Some discussion in the literature builds on the recognition that adult services in health and social care are invariably of a different type and level and an increase in self-management is therefore a key component of successful transitions.

Service gaps

Health and social care for young people with LD is marked by significant service gaps, in particular in mental health, social services and access to specialist services such as physiotherapy and SLT. The fact that these gaps occur at the time of other transitions adds an element of complexity to the transition process and increases the frustration and disappointment for young people and their families who often have to navigate this transition pretty much on their own.

Main factors contributing to the challenge of smooth transition are needs assessments, eligibility criteria and high eligibility thresholds in the adult sector, as well as organisational fragmentation in the NHS. The transition in health is often described as a transition into 'nowhere'. Joint clinics which are seen as helpful are not organised routinely for all young people with LD in the acute sector.

The literature notes that there is a chasm of expertise between the children and adult sector where knowledge about what works for the individual is simply not forwarded to, and used by, staff in the adult sector. The informational continuity of care is broken and hence organisational continuity is difficult to achieve (Freeman et al. 2001; Parker, Corden, and Heaton 2011). Hopes that GPs can step into the gap are often seen as too optimistic given their workload and only peripheral involvement with children with LD.

Evidence in the Welsh Context

Health and social care transition is poorly evidenced within the Welsh context. We could not identify any studies relevant to this rapid review that have been conducted within Wales or had taken place in similar settings in the UK. Anecdotal evidence indicates that transitions for some young people with LD and complex health needs may be significantly delayed. There is also some debate in the public around cross border care provision for which, again, there is little data available in the public domain. There is also a particular need to explore the impact on transition planning of non-coterminuous boundaries between social services (local authorities) and health care (local health boards).

Priorities for future work

Health and social care transitions are less researched than educational transition. This reflects the fact that education has been the main focus of attention of governmental policy. Social care transitions are often discussed as associated with good educational transition. Yet health care transitions remain one of the most difficult and under-researched transitions except housing. There are several messages emerging from the literature with regard to future work. They may be differentiated between social care and health care.

Within social care, more attention is required to investigate how to ensure needs assessments take place early enough to prevent a breakdown of care. There also needs to be further work undertaken to test the effectiveness of key working during transition and in the adult sector. It is not clear yet that key workers sign posting young people to adult services are effectively assisting young people with LD of all levels to navigate the adult care provision. Whilst key working in adult care would

constitute a significant additional resource, its value for many needs to be demonstrated rather than assumed.

With regard to the NHS, transition remains hamstrung by the fact of adult sector specialist fragmentation. More work needs to be done to understand which groups of young people with LD fail to access NHS services and why. In the tertiary health care sector, mental health services need to close the gap between children and adult sector provision, especially for those young people not in education between the ages of 16 and 18.

Overall, given widespread realism amongst observers about the limited ability of NHS services to change, the question as to how young people and their families can be prepared for a possible temporary disruption of care during transition appears to be more pertinent. Perhaps, an increase in the self-management of health conditions and an increased reliance on family and social assets may help young people negotiate the transition process better.

Housing

General context

There is some good research about the effects of housing on social inclusion and challenging behaviour for adults with LD (Felce 2016). There is also some evidence about the effects of out of area placements for young people attending residential colleges (PERRY et al, 2007). However, transition from home to independent living itself is an under-researched aspect of transition.

Whilst young people with LD consistently identify living away from home as an ambition just like their non-disabled peers, housing is poorly integrated into existing transition pathways in education, social care or health. How to facilitate good housing transitions is rarely investigated and we could only find 3 papers relevant to this review. Housing, whilst broached in most transition planning meetings in school, is not addressed as a significant concern or issue whilst young people are living with their parents. For those who plan to attend residential colleges, housing is provided through the educational institution and for most young people, housing post-college is often assumed to be within the family home again.

The exploration of different housing options, such as independent living or supported living, is opportunistic rather than routine and depends on whether the family or the young person identifies this as a preferred option. Assessments establish the eligibility and the housing needs of each young person.

The needs of young people

There is too little evidence to build a comprehensive picture about the needs of young people with LD with regard to housing. In line with normalisation models, young people are presumed to want to live on their own at some point, but there is little research about who gets which service and whether or not the support provided is of sufficient quality and scope to ensure a smooth transition from home to supported or independent living. It may be the case that moving to a residential out of area college is for many young people the only option to leave the family home temporarily. However, research does demonstrate the risks and disadvantages of out of area living at times of transition.

Service gaps

There is a question mark whether current transition planning processes sufficiently take account of young people's wish to live independently, and, equally, whether or not sufficient resources are made available for this. Yet, given that there is little conclusive research in this field, this must remain a field for future work.

Evidence in the Welsh Context

The issue of housing has mainly been examined through the lens of out of area placements which has particular salience in the Welsh context. However, there is no specific evidence relating to the housing needs of young people during transition from children to adult services. This echoes the relative absence of any reliable evidence in the housing transition for this population in other contexts. There is an urgent need to scope the extent to which housing is included in the statutory and post-college transition planning process. There is also a need to collect data on transition outcomes in housing, stratified for specific groups of young people with LD. The assumption, extrapolated from international evidence, would be that young people in Wales also experience a delayed transition to independent living depending on their support needs and the availability of housing in the local economy. Delayed transitions, in turn, may prevent holistic integrated transition planning across life domains.

Priorities for future work

The lack of reliable evidence in this field clearly sets out the need for further research on housing. There are four investigative domains in this respect. First, there is a need for reliable data on what the preferences of young people are, and whether or not they can pursue meaningfully the option of independent living at the time they become adults. With some research suggesting that up to 40 percent of young people are not being consulted in their own transition planning, it appears difficult to believe that the voices of young people are heard, listened to and acted upon where they express a preference for living away from home.

Second, it appears essential to scope the support made available by local services to assist young people who want to move into independent living to make their dream come true. We need a comprehensive picture about the support available, how it differs across Wales and how effective it is in bringing about independent living for this population.

Third, it appears important to gather evidence about what works in this context and for whom. Young people with LD are a distinctly heterogeneous group in their support needs and it is of significant importance to identify the types of support that are effective for people with different needs. A simple stratification approach may be helpful here when analysing national outcome data.

There is, fourth, the need to examine to what extent the current transition planning is effective in allowing young people to articulate housing preferences and whether or not the current framework of transition planning is the best way for services to actively develop opportunities for this group. We know that young people with LD only formulate personal preferences when experiencing various alternative options first hand (Kaehne 2009). Abstract contemplation of different options does not provide a robust foundation for young people with LD to make informed choices.

Unlike any other aspect of transition, housing poses considerable challenges in this regard as failed transitions into independent living may create undue emotional and financial costs for all stakeholders. It may therefore be more suitable to detach the housing transition from the general mandatory transition planning during adolescence and create a parallel process that commences at

a later stage. There is no reliable evidence about the advantages or disadvantages for either way at present. But testing the effectiveness of the integrated holistic transition process where housing options are explored at the same time as post-educational and social care transition is important if we want to secure the best outcomes for young people with LD.

General papers

Our search and analysis identified a range of papers that were not dealing with any specific aspect of transition but looked at the process in the round to draw conclusions about the way in which it works and how effective it is for young people. Since transition planning is a statutory process combining the various service sectors education, health, and social care, it seemed reasonable to include some summary comments on the process as a whole.

A consistent comment throughout many papers relates to the ability of young people to be heard throughout the process. Commentators and researchers repeatedly articulated a concern that young people are still not being listened to and their preferences are not being acted upon.

In addition, there has been a marked shift in social care to approaches utilising concepts such as resilience and asset-based analysis. There are some comments expressing that this may be helpful for transition in some areas whilst only masquerading the fact of limited resources in others. To ensure equity of service across the population it appears important to standardise any best practice approach.

There are also some concerns amongst observers that peer to peer support through parental networks may constitute an underused resource. Moreover, the introduction of person-centred planning has attracted some comments. The tenor of comments is that, at present, person-centred planning has not brought about the necessary shift from providing services *to* young people to creating services *around the needs* of the young person. Whilst there is an acknowledgement that services are moving in the right direction, there is much more to be done in order to provide genuinely person-centred services during transition.

There is also a recognition articulated in many comment pieces that there is often a conspicuous lack of hard data about transition destinations and that most research in the field has traditionally been of small scale and/or qualitative studies. Whilst those studies have generated a good amount of evidence on what young people want, how they and their families perceive the transition process and how they feel it can be improved, it remains difficult to associate different service models or support models with outcomes of transition. Measuring the outcomes of transition however is seen as critical to improve the process for everyone.

One specific area of transition which is widely presumed to be under-researched is the role of siblings. There have been some studies of their feelings and perceptions of the transition process but there is still a lack of understanding how they can influence the transition process and what their role may be in assisting their disabled brother or sister to navigate the move from children to adult services.

Recommendations

- Evaluate the impact of the Welsh additional learning needs strategy on transition planning and transition outcomes for young people
- Obtain and analyse data regarding transition outcomes/destinations for young people with LD in Wales
- Explore the barriers to include all young people with LD in their transition planning in school and FE colleges
- Obtain national data on destinations and transition outcomes of school leavers and those leaving colleges to ascertain access rates of young people to employment support
- Examine the facilitators and hindrances to include SE employment options in the transition planning for every young person in school and college
- Identify suitable ways to disseminate best practice in supported employment across Wales and facilitate shared learning in the field
- Gather relevant data on health transitions of young people with LD in Wales
- Review transition tools developed by Welsh local authorities and health care providers and assess their effectiveness
- Obtain and analyse relevant Welsh data pertaining to housing transitions
- Identify capacity of the housing sector to provide suitable supported living opportunities for young people in line with future demand
- Identify trends in, and reasons for, out of area/residential placements for young people moving from school to college

References

- Anon. 2002. "Clinical Governance Review at North Cumbria Mental Health and Learning Disabilities NHS Trust."
- Beyer, Stephen. 2005. *Rights of People with Intellectual Disabilities. Access to Education and Employment*. Budapest: Open Society Institute.
- Beyer, Stephen and Axel Kaehne. 2008. "The Transition of Young People With Learning Disabilities to Employment: What Works?" *Journal on Developmental Disabilities* 14(1):81–90.
- Beyer, Stephen, Axel Kaehne, Jill Grey, Kim Sheppard, and Andrea Meek. 2008. *What Works? Transition to Employment for Young People with Learning Disabilities*. Chippenham: Shaw Trust.
- Felce, David. 2016. "Community Living for Adults with Intellectual Disabilities: Unravelling the Cost Effectiveness Discourse." *Journal of Policy and Practice in Intellectual Disabilities*. Retrieved (<https://liverpool.idm.oclc.org/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2016-59916-001&site=ehost-live&scope=site>).
- Freeman, George et al. 2001. *Continuity of Care. Report of a Scoping Exercise for the NCCSDO*. London: Service Delivery Organisation Programme NIHR.
- Ganann, Rebecca, Donna Ciliska, and Helen Thomas. 2010. "Expediting Systematic Reviews: Methods and Implications of Rapid Reviews." *Implementation Science* 5(1).
- Harker, Julie and Jos Kleijnen. 2012. "What Is a Rapid Review? A Methodological Exploration of Rapid Reviews in Health Technology Assessments." *International Journal of Evidence-Based Healthcare* 10(4):397–410.
- Kaehne, Axel. 2009. "Choice for Young People with Learning Disabilities in Post-Education Transition." *Mental Health Review Journal* 14(2):37–43.
- Kaehne, Axel. 2010. "Multi-Agency Protocols in Intellectual Disabilities Transition Partnerships: A Survey of Welsh Local Authorities." *Journal of Policy and Practice in Intellectual Disabilities* 7(3):182–88.
- Kaehne, Axel and Stephen Beyer. 2013. "Person-Centred Reviews as a Mechanism for Planning the Post-School Transition of Young People with Intellectual Disability." *Journal of Intellectual Disabilities Research* 1–11. Retrieved (<http://onlinelibrary.wiley.com/store/10.1111/jir.12058/asset/jir12058.pdf?v=1&t=hilo4kye&s=149699b35b42a086d6e1fe4f3bd42cf67bbd899b>).
- Kaltenthaler, Eva et al. 2016. "The Use of Rapid Review Methods in Health Technology Assessments: 3 Case Studies." *BMC Medical Research Methodology* 16(1):108. Retrieved (<http://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-016-0216-1>).
- Khangura, Sara, Kristin Konnyu, Rob Cushman, Jeremy Grimshaw, and David Moher. 2012. "Evidence Summaries: The Evolution of a Rapid Review Approach." *Systematic Reviews* 1(1).
- Moore, Gabriel, Sally Redman, Sian Rudge, and Abby Haynes. 2018. "Do Policy-Makers Find Commissioned Rapid Reviews Useful?" *BMC Health Research Policy and Systems* 1–14. Retrieved (<https://health-policy-systems.biomedcentral.com/track/pdf/10.1186/s12961-018-0293-1?site=health-policy-systems.biomedcentral.com>).
- Parker, Gillian, Anne Corden, and Janet Heaton. 2011. "Experiences of and Influences on Continuity of Care for Services Users and Carers: Synthesis of Evidence from a Research Programme." *Health and Social Care in the Community* 19(6):576–601.
- PERRY, David W. and al et. 2007. "Why Are People with Intellectual Disability Moved 'out-of-Area'?" *Journal of Policy and Practice in Intellectual Disabilities* 4(3):203–209. Retrieved (<http://www.blackwellpublishing.com/journal.asp?ref=1741-1122&>).
- Tricco, Andrea C. et al. 2015. "A Scoping Review of Rapid Review Methods." *BMC Medicine* 13(1).
- Varker, Tracey et al. 2015. "Rapid Evidence Assessment: Increasing the Transparency of an

Emerging Methodology." *Journal of Evaluation in Clinical Practice* 21(6):1199–1204.

Watt, Amber et al. 2008. "Rapid versus Full Systematic Reviews: Validity in Clinical Practice?" *ANZ Journal of Surgery* 78(11):1037–40.

Appendices

Appendix 1 – Databases searched with results

| Database/website | Date searched | Results |
|---|---------------|--|
| Medline (OVID) | 19/12/2017 | 478 |
| CINAHL (EbscoHost) | 19/12/2017 | 380 |
| PsycInfo (EbscoHost) | 19/12/2017 | 1630 |
| HMIC (HDAS) | 19/12/2017 | 31 |
| NICE Evidence Search | 28/12/2017 | 99 |
| BEI (EbscoHost) | 28/12/2017 | 35 |
| ERIC (EbscoHost) | 28/12/2017 | 157 |
| ASSIA (ProQuest) | 03/01/2017 | 163 |
| Social Care Online | 28/12/2017 | 202 |
| Web of Science | 28/12/2017 | 314 |
| Campbell Systematic Reviews | 28/12/2017 | 3 |
| EPPI | 28/12/2017 | 22 |
| Google Scholar | 4/1/18 | 113 |
| Child Development & Adolescent Studies (EbscoHost) | 3/1/17 | 23 |
| Discover More | 28/12/17 | 30 |
| Key Journals | | |
| Learning Disability Today https://www.learningdisabilitytoday.co.uk | 3/1/18 | 84 |
| Llais - Learning Disability Wales https://www.ldw.org.uk/ | 3/1/18 | 14 |
| Learning Disability Nursing https://www.learningdisabilitynurse.com/ | 3/1/18 | 4 |
| Nursing Times https://www.nursingtimes.net | 3/1/18 | 40 |
| Learning Disability Practice https://journals.rcni.com/learning-disability-practice | 3/1/18 | 109 |
| Journal of Adolescent Health http://www.jahonline.org | 3/1/18 | 151 |
| Journal of Vocational Rehabilitation https://content.iospress.com/journals/journal-of-vocational-rehabilitation/47/3 | 3/1/18 | 132 |
| The British Journal of Learning Disabilities http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156 | 3/1/18 | 7 (transition in title field) 28 (transition in abstract field) |

Appendix 2 – Example of search terms (Medline)

1 exp Intellectual Disability/ (96871)
2 "additional learning need*".tw. (8)
3 exp Learning Disorders/ (24265)
4 "learning disabilit*".tw. (7787)
5 "intellectual disabilit*".tw. (10915)
6 exp Cognition Disorders/ (87881)
7 "cognitive disabilit*".tw. (857)
8 exp Developmental Disabilities/ (19588)
9 "developmental disabilit*".tw. (4140)
10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (226304)
11 exp Transition to Adult Care/ (932)
12 exp Health Transition/ (1068)
13 (transition or transitioning or transitional or transition-age).tw. (224311)
14 exp Young Adult/ or exp Adolescent/ (2338983)
15 adolescen*.tw. (222328)
16 paediatric*.tw. (51720)
17 pediatric*.tw. (232478)
18 "emerg* adult*".tw. (1639)
19 "early adult*".tw. (5862)
20 "young adult*".tw. (75084)
21 "young person".tw. (833)
22 "young people".tw. (21016)
23 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (2575848)
24 12 or 13 (224999)
25 23 and 24 (17646)
26 exp Adult/ or exp Young Adult/ or adult*.tw. (7556286)
27 18 or 19 or 20 or 21 or 22 or 26 (7565076)
28 exp Adolescent/ (2011431)
29 15 or 16 or 17 or 28 (2212453)
30 24 and 27 and 29 (11115)
31 11 or 25 or 30 (17835)
32 10 and 31 (519)
33 limit 32 to (english language and yr="1990 -Current") (478)

Appendix 3 – List of papers included in the analysis

Education

- Schwartz, K., Mactavish, J. and Lutfiyya Marie, Z. (2006), "Making community connections: Educator perspectives on transition planning for students with intellectual disabilities.", *Exceptionality Education Canada*, Vol. 16 No. 2, p. 73.
- Lehmann, J.P., Bassett, D.S. and Sands, D.J. (1999), "Students' participation in transition-related actions: A qualitative study", *Remedial and Special Education*, SAGE PUBLICATIONS, INC., Austin, Vol. 20 No. 3, p. 160.
- Hartman, M.A. (2009), "Step by step: Creating a community-based transition program for students with intellectual disabilities", *Teaching Exceptional Children*, Vol. 41 No. 6, pp. 6–11.
- Dauncey, M. (2016), "Additional Learning Needs (ALN) in Wales: 7 December 2016".
- Routledge, M. (2000), "Collective responsibilities, fragmented systems: transition to adulthood for young people with learning disabilities.", *Tizard Learning Disability Review*, Vol. 5 No. 4, pp. 17–27.
- Disabilities, A.A. of P.C. on C.W. (2000), "The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. American Academy of Pediatrics. Committee on Children With Disabilities.", *Pediatrics*, United States, Vol. 106 No. 4, pp. 854–856.
- Gallagher, T. and Bennett, S. (2012), "Does inclusion make a difference? Young adults with intellectual disabilities transitioning from school into community", *Journal of Intellectual Disability Research*, (Gallagher) Brock University, Faculty of Education, St. Catharines, ON, Canada, Vol. 56 No. 7–8.
- Kohler, P.D. and Field, S. (2003), "Transition-focused education: Foundation for the future", *The Journal of Special Education*, SAGE PUBLICATIONS, INC., Bensalem, Vol. 37 No. 3, pp. 174–183.
- Foley, K.-R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., Einfeld, S., et al. (2013), "Functioning and post-school transition outcomes for young people with Down syndrome.", *Child: Care, Health and Development*, England, Vol. 39 No. 6, pp. 789–800.
- Leonard, H., Foley, K.-R., Pikora, T., Bourke, J., Wong, K., McPherson, L., Lennox, N., et al. (2016), "Transition to adulthood for young people with intellectual disability: the experiences of their families.", *European Child & Adolescent Psychiatry*, Germany, Vol. 25 No. 12, pp. 1369–1381.
- Neubert, D.A. and Redd, V.A. (2008), "Transition services for students with intellectual disabilities: A case study of a public school program on a community college campus.", *Exceptionality*, Taylor & Francis, Neubert, Debra A., Department of Special Education, University of Maryland, College Park, MD, US, 20742, Vol. 16 No. 4, pp. 220–234.

- Abbott, D. and Heslop, P. (2008), "Where next? Transition pathways for young people with learning difficulties in UK Residential Schools and Colleges", *Journal of Developmental Disabilities*, Vol. 14 No. 1, pp. 52–58.
- Papay, K. and Bambara, M. (2014), "Best practices in transition to adult life for youth with intellectual disabilities.", *Career Development and Transition for Exceptional Individuals*, Vol. 37 No. 3, p. 136.
- WILSON, H. and et, al. (2012), "Heidi's and Philip's stories: transitions to post-secondary education", *British Journal of Learning Disabilities*, Wiley-Blackwell, Vol. 40 No. 2, pp. 87–93.
- Carter, E.W., Brock, M.E. and Trainor, A.A. (2014), "Transition Assessment and Planning for Youth With Severe Intellectual and Developmental Disabilities", *The Journal of Special Education*, PRO-ED Journals, Austin TX, Vanderbilt University, Nashville, TN, USA, Vol. 47 No. 4, pp. 245–255.
- Raghavan, R., Pawson, N. and Small, N. (2013), "Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity.", *Journal of Intellectual Disability Research*, Vol. 57 No. 10, p. 936.
- McConkey, R. and Smyth, M. (2001), "Reflections of parents and students with severe learning difficulties on their special schooling and the transition to post-school provision.", *Journal of Research in Special Educational Needs*, Blackwell Publishing, McConkey, Roy, School of Health Sciences, University of Ulster, Newtownabbey, Northern Ireland, BT37 0QB, Vol. 1 No. 3, available at:
<https://liverpool.idm.oclc.org/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2006-12580-003&site=ehost-live&scope=site>.
- Kaehne, A. and Beyer, S. (2014), "Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability", *Journal of Intellectual Disability Research*, Blackwell Publishing Ltd, Vol. 58 No. 7, pp. 603–613.
- Durlak, C.M., Rose, E. and Bursuck, W.D. (1994), "Preparing high school students with learning disabilities for the transition to postsecondary education: teaching the skills of self-determination.", *Journal of Learning Disabilities*, United States, Vol. 27 No. 1, pp. 51–59.
- GILLAN, D. and COUGLAN, B. (2010), "Transition from special education into postschool services for young adults with intellectual disability: Irish parents' experience", *Journal of Policy and Practice in Intellectual Disabilities*, Wiley-Blackwell, Vol. 7 No. 3, pp. 196–203.
- Smart, M. and Smart, M. (2004), "Transition planning and the needs of young people and their carers: the alumni project", *British Journal of Special Education*, United Kingdom, September.
- TARLETON, B. and WARD, L. (2005), "Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition", *British Journal of Learning Disabilities*, Wiley-Blackwell, Vol. 33 No. 2, pp. 70–76.
- DYKE, P. and et, al. (2013), "The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life", *Journal of Intellectual and Developmental Disability*, Informa Healthcare, Vol. 38 No. 2, pp. 149–162.

- Carnaby, S. and al.], S.C.. . [e. (2003), "Participation in transition review meetings: a case study of young people with learning disabilities leaving a special school", *British Journal of Special Education*, United Kingdom, December.
- Pallisera, M., Vilà, M., Fullana, J., Castro, M., Puyaltó, C. and Díaz-Garolera, G. (2017), "Proposals for improving the transition process of young people with intellectual disabilities in Spain: insights from focus groups of professionals, young people and their families", *European Journal of Special Needs Education*, pp. 1–15.
- Tur-Kaspa, H. (2002), "The socioemotional adjustment of adolescents with LD in the kibbutz during high school transition periods.", *Journal of Learning Disabilities*, United States, Vol. 35 No. 1, pp. 87–96.

Employment

- White, W.J. (1992), "The postschool adjustment of persons with learning disabilities: current status and future projections", *Journal of Learning Disabilities*, Vol. 25 No. Aug/Sep 92, pp. 448–456.
- JACOBSEN, Y. (2002), *Making the Jump: Transition to Work; a Guide to Supporting Adults with Learning Difficulties Make the Jump from Education to Employment*, National Institute for Adult Continuing Education, Leicester, available at: <http://www.skill.org.uk>.
- Fasching, H. (2014), "Vocational education and training and transitions into the labour market of persons with intellectual disabilities.", *European Journal of Special Needs Education*, Taylor & Francis, Fasching, Helga, Vol. 29 No. 4, pp. 505–520.
- Moon, S., Simonsen, M.L. and Neubert, D.A. (2011), "Perceptions of supported employment providers: What students with developmental disabilities, families, and educators need to know for transition planning.", *Education and Training in Autism and Developmental Disabilities*, Council for Exceptional Children/Div on Developmental Disabilities, Moon, Sherril, Department of Special Education, University of Maryland, 1308 Benjamin Building, College Park, MD, US, 20742, Vol. 46 No. 1, pp. 94–105.
- Lindstrom, L., Doren, B., Metheny, J., Johnson, P. and Zane, C. (2007), "Transition to Employment: Role of the Family in Career Development.", *Exceptional Children*, Vol. 73 No. 3, pp. 348–366.
- Cullen, M.A., Lindsay, G., Dockrell, J.E. and Mairi Ann Cullen, G.L. and J.E.D. (2009), "The role of the Connexions service in supporting the transition from school to post-16 education, employment training and work for young people with a history of specific speech and language difficulties or learning difficulties", *Journal of Research in Special Educational Needs*, United Kingdom, July.
- Gebhardt, M., Tretter, T., Schwab, S., Gasteiger-Klicpera, B. and Markus Gebhardt Susanne Schwab and Barbara Gasteiger-Klicpera, T.T. (2011), "The transition from school to the workplace for students with learning disabilities: status quo and the efficiency of pre-

vocational and vocational training schemes", *European Journal of Special Needs Education*, United Kingdom, November.

- Beyer, S., Meek, A. and Davies, A. (2016), "Supported work experience and its impact on young people with intellectual disabilities, their families and employers.", *Advances in Mental Health & Intellectual Disabilities*, Vol. 10 No. 3, pp. 207–220.
- Lindsay, S., R Hartman, L. and Fellin, M. (2016), "A systematic review of mentorship programs to facilitate transition to post-secondary education and employment for youth and young adults with disabilities.", *Disability and Rehabilitation*, England, Vol. 38 No. 14, pp. 1329–1349.
- Noel, V.A., Oulvey, E., Drake, R.E. and Bond, G.R. (2017), "Barriers to Employment for Transition-age Youth with Developmental and Psychiatric Disabilities.", *Administration and Policy in Mental Health*, United States, Vol. 44 No. 3, pp. 354–358.
- Foley, K.R., Dyke, P., Girdler, S., Bourke, J. and Leonard, H. (2012), "Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF.", *Disability and Rehabilitation: An International, Multidisciplinary Journal*, Vol. 34 No. 20, p. 1747.
- KAEHNE, A. and BEYER, S. (2013), "Supported employment for young people with intellectual disabilities facilitated through peer support: a pilot study", *Journal of Intellectual Disabilities*, Sage, London, Vol. 17 No. 3, pp. 236–251.
- Wehman, P., Chan, F., Ditchman, N. and Kang, H.J. (2014), "Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: A case control study", *Intellectual and Developmental Disabilities*, Vol. 52, pp. 296–310.
- Kaehne, A. and Beyer, S. (2008), "Carer perspectives on the transition of young people with learning disabilities to employment.", *Journal on Developmental Disabilities*, Ontario Assn on Developmental Disabilities, Vol. 14 No. 1, pp. 95–104.
- Beyer, S. and Kaehne, A. (2008), "The Transition of Young People With Learning Disabilities to Employment: What Works?", *Journal on Developmental Disabilities*, Vol. 14 No. 1, pp. 81–90.
- Kilsby, M. and Beyer, S. (1996), "Engagement and interaction: A comparison between supported employment and day service provision", *Journal of Intellectual Disability Research*, Vol. 40, pp. 348–357.
- Beyer, S., Kaehne, A., Grey, J., Sheppard, K. and Meek, A. (2008), *What Works? Transition to Employment for Young People with Learning Disabilities - Final Report*, Welsh Centre for Learning Disabilities, Cardiff.

Health and Social Care

- Schrander-Stumpel, C.T.R.M., Sinnema, M., Van Den Hout, L., Maaskant, M.A., van Schrojenstein Lantman-de Valk, H., Wagemans, A., Schrander, J.J.P., et al. (2007), "Healthcare transition in persons with intellectual disabilities: General issues, the Maastricht model, and Prader–Willi syndrome", *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, Vol. 145, Wiley Online Library, pp. 241–247.
- Kirkendall, A., Doueck, H.J. and Saladino, A. (2009), "Transitional Services for Youth With Developmental Disabilities", *Research on Social Work Practice*, Sage Publications, Thousand Oaks CA, University at Buffalo, State University of New York, Vol. 19 No. 4, pp. 434–445.
- Nguyen, T., Henderson, D., Stewart, D., Hlyva, O., Punthakee, Z. and Gorter, J.W. (2016), "You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management.", *Child: Care, Health and Development*, England, Vol. 42 No. 4, pp. 464–472.
- Stewart, D. (2009), "Transition to adult services for young people with disabilities: current evidence to guide future research.", *Developmental Medicine and Child Neurology*, Vol. 51, p. 169.
- Rosenbaum, P. and Stewart, D. (2007), "Perspectives on transitions: rethinking services for children and youth with developmental disabilities.", *Archives of Physical Medicine and Rehabilitation*, Vol. 88 No. 8, p. 1080.
- BARRON, D.A. and et, al. (2013), "Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services", *Health and Social Care in the Community*, Wiley-Blackwell, Vol. 21 No. 3, pp. 283–292.

Housing

- Sitlington, L. (1996), "Transition to living: The neglected component of transition programming for individuals with learning disabilities.", *Journal of Learning Disabilities*, Vol. 29 No. 1, p. 31.
- KIRKENDALL, A., DOUECK, H.J. and SALADINO, A. (2009), "Transitional services for youth with developmental disabilities: living in college dorms", *Research on Social Work Practice*, Sage, Vol. 19 No. 4, pp. 434–445.
- ALBORZ, A. (2003), "Transitions: placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision", *Journal of Applied Research in Intellectual Disabilities*, Wiley-Blackwell, Vol. 16 No. 1, pp. 75–88.

General papers

- Gauthier-Boudreault, C., Gallagher, F. and Couture, M. (2017), "Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing?", *Research in Developmental Disabilities*, Vol. 66, pp. 16–26.
- St Quintin, P., Disney, J. and Disney, P.S.Q. and J. (2003), "Transition: the experiences of young people and their families in England", *Tizard Learning Disability Review*, United Kingdom, October.
- Pallisera, M., Fullana, J., Puyaltó, C. and Vilà, M. (2016), *Changes and Challenges in the Transition to Adulthood: Views and Experiences of Young People with Learning Disabilities and Their Families.*, *European Journal of Special Needs Education*, Vol. 31, pp. 391–406.
- CONLON, L. (2014), *Transition Planning for Young People with Learning Disabilities in Great Britain*, Northern Ireland Assembly. Research and Information Service, Belfast, available at: http://www.niassembly.gov.uk/Documents/RaISe/Publications/2014/employment_learning/6514.pdf.
- SMALL, N., RAGHAVAN, R. and PAWSON, N. (2013), "An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning", *Journal of Intellectual Disabilities*, Sage, London, Vol. 17 No. 4, pp. 283–300.
- Kim, K.-H. and Turnbull, A. (2004), "Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning.", *Research and Practice for Persons with Severe Disabilities*, Vol. 29 No. 1, p. 53.